

REPORT TO THE IOWA GENERAL ASSEMBLY

ANATOMICAL GIFTS

ANNUAL DONATION AND COMPLIANCE REPORT

FOR THE CALENDAR YEAR 2008

Submitted by

Iowa Department of Public Health

in conjunction with the

Iowa Donor Network

and the Iowa Lions Eye Bank

Introduction

Iowa is served by one organ procurement organization, the Iowa Donor Network (IDN), and a single eye recovery agency, the Iowa Lions Eye Bank (ILEB). Through a contract with ILEB, IDN serves as the human tissue referral agency (eyes, bone, skin, tendons and heart valves) for the state. ILEB conducts cornea recovery, processing, evaluation, and distribution services. The organizations cooperate closely with Iowa hospitals to promote and accomplish organ, tissue, and eye donations.

In 1996, the Iowa legislature created the Anatomical Gift Public Awareness and Transplantation Fund. County treasurers seek contributions to this fund when Iowans register or renew registration on their motor vehicles. In 2004, an organ and tissue donation awareness license plate was created for Iowa motorists. A \$35 charge for the plate plus \$10 renewal fee, in addition to the normal fee, is provided to the awareness fund. The Anatomical Gift Public Awareness Advisory Committee advises the Iowa Department of Public Health (IDPH) on grants to be made from contributed funds. Iowa Code Chapter 142C.17 requires the department, in conjunction with any statewide organ procurement organization, to submit an annual donation and compliance report.

Organs, Tissues, and Eye Donors

The number of organ donors in Iowa (January through September):

2008	47
2007	42
2006	32

Through the same period for tissue donors:

2008	300
2007	264
2006	210

Through the same period for transplant and research eye donors:

	Transplant	Research
2008	396	234
2007	317	187
2006	258	202

Thanks to increased awareness and a relationship with the Iowa Department of Transportation (DOT), Motor Vehicle Division, organ and tissue donor rates continue to rise.

Organs, Tissues, and Eye Donors

As mandated by the Centers for Medicare and Medicaid, IDN receives a referral call on every death in Iowa hospitals, but not every referral results in a suitable organ, tissue or eye donation. Consent for donation and medical suitability must also be considered. The 47 organ donors this year contributed 165 organs for transplantation.

Each tissue donor (on average) provides enough transplantable tissue for up to 50 people. We can expect approximately 15,000 people will receive transplantable tissue needed for life-saving and life-enhancing procedures this year.

On average, each eye donation for transplant provides sight to two people, and provides tissue for scleral patch grafts for eye traumas and glaucoma shunt surgeries. In the past few years, corneal transplantation surgical techniques have advanced and now provide options that improve visual outcomes in a shorter period of time, increasing the amount of sight that is restored and decreasing the time it takes to recover sight after a transplant. As a result, transplants are being performed earlier and more frequently than before, saving sight earlier and decreasing the trauma of losing sight. Even though donations are increasing, we are still not keeping up with the demand in Iowa, and in 2008 had to import 76 corneas for transplantation. We are fortunate that, for the most part, we are able to meet the need for corneal transplantation in Iowa.

Iowa eyes donated for research are given to the University of Iowa John and Marcia Carver Center for Macular Degeneration researchers, and this year donated eyes have contributed to advances in three areas of blinding eye disease:

- Glaucoma researchers, searching for the mechanisms that activate the disease of glaucoma, have discovered through their work with mice that an inappropriate activation of the immune system may be responsible. They are now utilizing human donated eyes to see if the same process activates glaucoma in people. If they discover the process that starts the disease, then they will begin to work on ways to stop that process. Glaucoma is the leading cause of blindness in the world.
- Blinding eye diseases caused by a genetic defect are being investigated by looking at the genes in human eyes, with the result being that the first genetic intervention for one blinding eye disease, Leber's Congenital Amaurosis (LCA) is currently being trialed in humans. While the results are not available yet, correcting the same LCA genetic defect in a Briard dogs' eyes has been successful, so researchers are hopeful that genetic treatments will help people in the future. LCA causes babies to be born blind or children to go blind before they reach school age, and currently there is no treatment or cure.

- Age Related Macular Degeneration (AMD) researchers have discovered one pathway for activation of the disease, and are currently working on a way to interrupt that pathway. They hope to have something available in the near future that will stop the macular degeneration in more than 70 percent of the people affected. The pathway that was discovered also plays a role in heart disease, Alzheimer's, and abdominal aortic aneurysms.

Medicare Rules

In August of 1998, the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) promulgated regulations designed to increase organ tissue and eye donation. The rules are part of the Hospital Conditions of Participation for the Medicare and Medicaid programs. The rules require "a hospital to have an agreement with the Organ Procurement Organization (OPO) designated by the Secretary of the Department of Health and Human Services (DHHS), under which the hospital will contact the OPO in a timely manner about individuals who die, or whose deaths are imminent in the hospital. The OPO will then determine each individual's medical suitability for donation. The hospital must also have an agreement with at least one tissue bank and at least one eye bank to cooperate in the retrieval, processing, preservation, storage and distribution of tissue and eyes, as long as the agreement does not interfere with organ donation. The final rule requires a hospital to ensure, in collaboration with the OPO with which it has an agreement; the family of every potential donor is informed of its option to donate organs or tissues or eyes, or not to donate."

Contributions

Contributions provided through county treasurers and the license plate program to the Anatomical Gift Public Awareness and Transplantation Funds were \$69,076 in fiscal year 2008. This is \$8,169 more than provided in fiscal year 2007. This revenue represents a rate of \$0.023 per capita (based on estimated 2006 population of 2,982,085 per the U.S. Census Bureau). The county treasurers, the Anatomical Gift Public Awareness Advisory Committee, IDN and ILEB continue to explore ways to increase awareness of the contribution opportunity and contributions to the fund.

Community Grants

Payment from the Anatomical Gift Public Awareness and Transplantation Fund totaled \$48,766 in fiscal year 2008. This included public awareness activities, organ transplantation procedures and related patient costs, and support of the donor registry. Of these payments, \$175 covered administrative costs.

Donor Registry

Chapter 1052, Acts of the 2000 General Assembly, authorized the director of IDPH to contract for the establishment of a statewide organ and tissue donor registry. As specified, the contract provides for a centralized database and automated system to make organ, tissue, and eye donor information available to family members and physicians seven days a week, twenty-four hours a day. IDN launched the Iowa Donor Registry (www.iowadonorregistry.org) on March 18, 2002. To date, more than 574,000 Iowans have registered their intentions to become organ, tissue, and eye donors upon death. In 2007, the Revised Uniform Anatomical Gift Act was passed by the legislature requiring DOT to provide the Iowa Donor Registry a listing with every Iowan who has marked “yes” to donation on a license, permit or identification card. DOT provides monthly downloads to the Iowa Donor Registry as a legal consent for donation according to Iowa law. This important legislation has increased the amount of registrants in the Iowa Donor Registry from an average of 2,000 registry entries per month to over 30,000 per month.

Summary

As indicated in this report, the organ, tissue, and eye donation programs continue to serve a significant number of Iowans. As of November 2008, the number of citizens waiting for lifesaving organ transplants had climbed to over 500. This increase over the previous period last year is due to several reasons. The University of Iowa has opened up a new lung transplant program and has hired several new transplant physicians. These actions increased the number of patients seeking transplants at the University, which increased the waiting list. Additionally, new corneal transplant techniques are resulting in these surgeries being performed earlier in the course of a blinding eye disease, rather than later, which has increased the demand for corneal tissue. Efforts to increase public awareness and acceptance of organ, tissue, and eye donation must continue and be fostered by every practicing nurse, physician, social worker, paramedic, law enforcement official, hospital administrator and funeral director in Iowa. The Anatomical Gift Public Awareness Advisory Committee, the Iowa Donor Network, the Iowa Lions Eye Bank, and the Iowa Department of Public Health will continue to promote increased organ, tissue, and eye donation and explore ways to increase public awareness of the opportunity to donate organs, tissues, and eyes.